Needs Assessment of Lymphoedema Services in Fife: Recommendations

Author: **Dr C. Bulley**
Work carried out in: Queen Margaret Hospital, NHS Fife
Funded by: Core Cancer Review Group in Fife

Lymphoedema is a chronic accumulation of tissue fluid, resulting from disruption to the lymphatic system. In developing countries, this is commonly due to treatments for breast cancer. It results in:

- **swelling**
- **pain**
- **acute inflammatory episodes**
- **reduced functional ability**
- **reduced quality of life**

(British Lymphology Society, 2001).

There are management strategies which can reduce and maintain fluid volume. These require specialist training and are usually carried out by nurses and physiotherapists. Although the evidence base is not highly developed, there is support for the efficacy of lymphoedema management, and consensus regarding specific strategies. These include:

- **compression**
- **exercise**
- **massage**
- **skin care**

(International Society of Lymphology Committee (1995).

In 2003, there was one specialist lymphoedema service in Fife, consisting of a 0.6 FTE physiotherapist, working in Queen Margaret Hospital. The Core Cancer Review Group in Fife commissioned a needs assessment of local lymphoedema services, to inform decisions regarding further development.

Lymphoedema was considered to represent a 'need' that could benefit from health care (Bulley, 2003). The epidemiological approach to needs assessment was used (Stevens et al., 2003); specific information sources included:

1) operational statistics provided by Queen Margaret Hospital Lymphoedema Service: 1996-2001

2) estimates of lymphoedema incidence: hospital admissions and diagnoses relating to lymphoedema between 1997 and 2002. Data were limited by their reliance on hospitalisation (Fife NHS Board Information Services, 2003, in Bulley, 2003).

3) estimates of lymphoedema prevalence from primary practices in Fife; data were limited by a poor response rate, lack of electronic databases for information retrieval, and the likelihood of non-diagnosis.

4) a telephone survey of referrers: 44 general practitioners from different Local Health Care Cooperatives

5) qualitative interviews with five lymphoedema service providers

6) qualitative interviews with five lymphoedema service clients

7) a forum of three lymphoedema service providers to discuss recommendations and ensure that they were clinically relevant

Table 1 summarises the main findings from the listed information sources and the resulting recommendations. These were divided into a three-stage plan to allow for incremental development as funding became available.

Table 1: Summary of the rationale for recommendations resulting from a needs assessment of lymphoedema services in Fife

Information Source	Main Findings	Recommendations
1 2 3 5	→ The specialist lymphoedema service in Fife is under pressure → Although incidence and prevalence estimates are very tentative, they suggest that the service must be well coordinated, but not extensive	Increase staffing to 2 full-time clinicians, ideally one physiotherapist and one nurse to fill two roles: → One specialist to carry out complex, intensive therapy → One keyworker to carry out assessments and maintenance therapy
4 5	→ Lymphoedema service clients with the greatest prior awareness of the disorder were most persistent in seeking referral → There was evidence that medical and allied health professionals lacked awareness of lymphoedema, the potential for management, and existing services → There was evidence of delayed diagnosis and referral for management	Ensure that specific roles are incorporated in the service: → provision of preventive advice to individuals at risk of developing lymphoedema → liaison with medical and allied health professionals in the acute and primary care settings to increase awareness and speed of referral
4 5 6	→ There was a geographical disparity in access to treatment and in relation to awareness of lymphoedema services expressed by medical professionals	→ Coordinate the service from a central acute setting; conduct initial assessments and follow-up maintenance therapy in 'roving' clinics based in primary practices → Incorporate an in-patient phase for intensive therapy and home visits for those who are unable to attend clinics → Educate local nursing and allied health professionals to enable them to supplement specialist services
7	There was some concern regarding: → the potential for blurring of the service boundaries → the likelihood that increased awareness of lymphoedema would lead to further pressure on the existing service → the needs of clients for psychosocial support	→ Develop referral criteria and service boundaries → Develop an audit and monitoring system → Negotiate the development of a client support group facilitated by the Maggie's Centre

For further detail, please contact the author at:
Physiotherapy, Queen Margaret University College, Leith Campus,
Duke Street, Edinburgh, EH6 8HF; 0131 317 3822; cbulley@qmuc.ac.uk

References:
British Lymphology Society (2001). *Chronic Oedema Population and Needs.* Available from: http://www.lymphoedema.org/bls/blsd0010.htm. [accessed 20/6/2003].
Bulley, C. (2003) *Needs Assessment of Lymphoedema Services in Fife.* Unpublished Report for the Core Cancer Review Group in Fife.
International Society of Lymphology Committee, (1995) The Diagnosis and Treatment of Peripheral Lymphedema: Consensus Document of the International Society of Lymphology Committee. *Lymphology*, 28: 113-117.
Stevens, A., Raftery, J. & Mant, J. (2003) An *Introduction to HCNA: The Epidemiological Approach to Health Care Needs Assessment.* Available From: http://hcna.radcliffe-oxford.com [accessed 11/2/2003].